

MS Caregiver Research and You!

MSCOE Caregiver Conference Call

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VA SCI/D and MS Social Workers



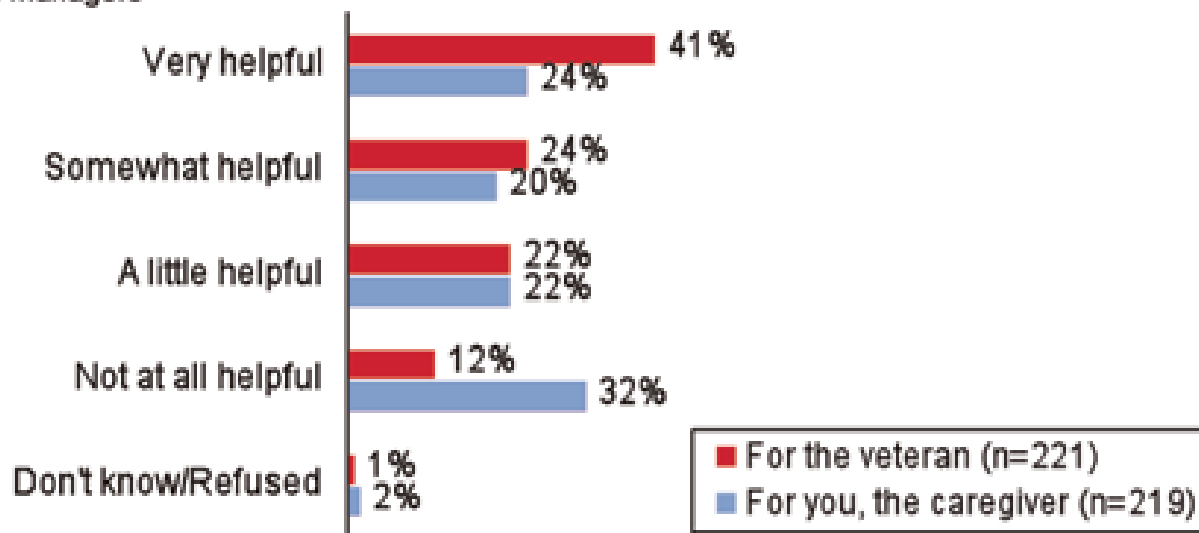
- 40,000 Veterans with MS; 16,000+ receive care at VA
- 42,000 Veterans with Spinal Cord Injury; 25,000 receive care at VA
- Utilize traditional social work roles to assist Caregivers and Veterans
 - Strengths- based
 - Client-centered
 - “Best Practice” models
 - Lead clients to a positive sense of self and interdependence

(MSCOE, 2012; Curtin, 2012)

How Helpful Are We To Caregivers?

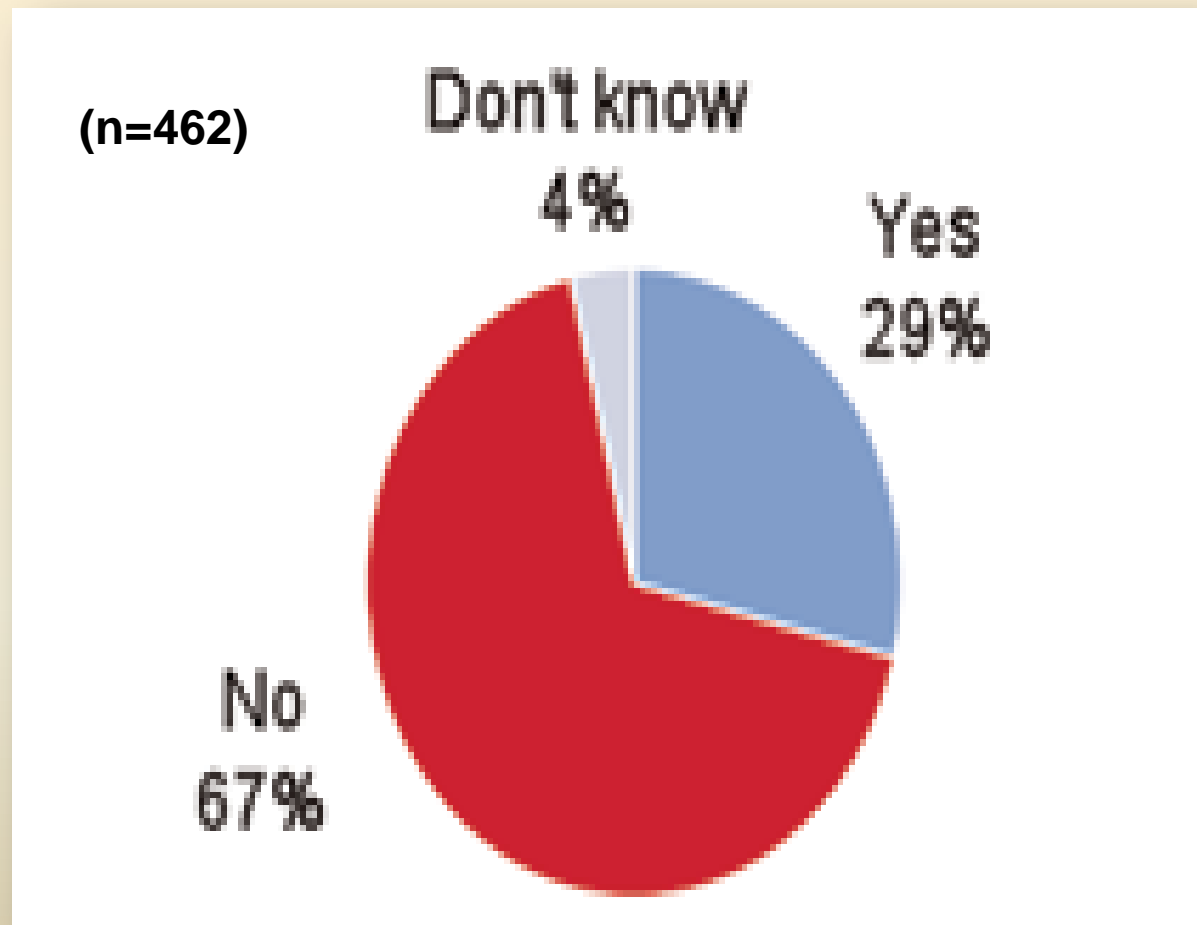
How helpful has the care/case manager or social worker been in locating, arranging, and coordinating suitable care and resources?

Veteran has one or more case managers



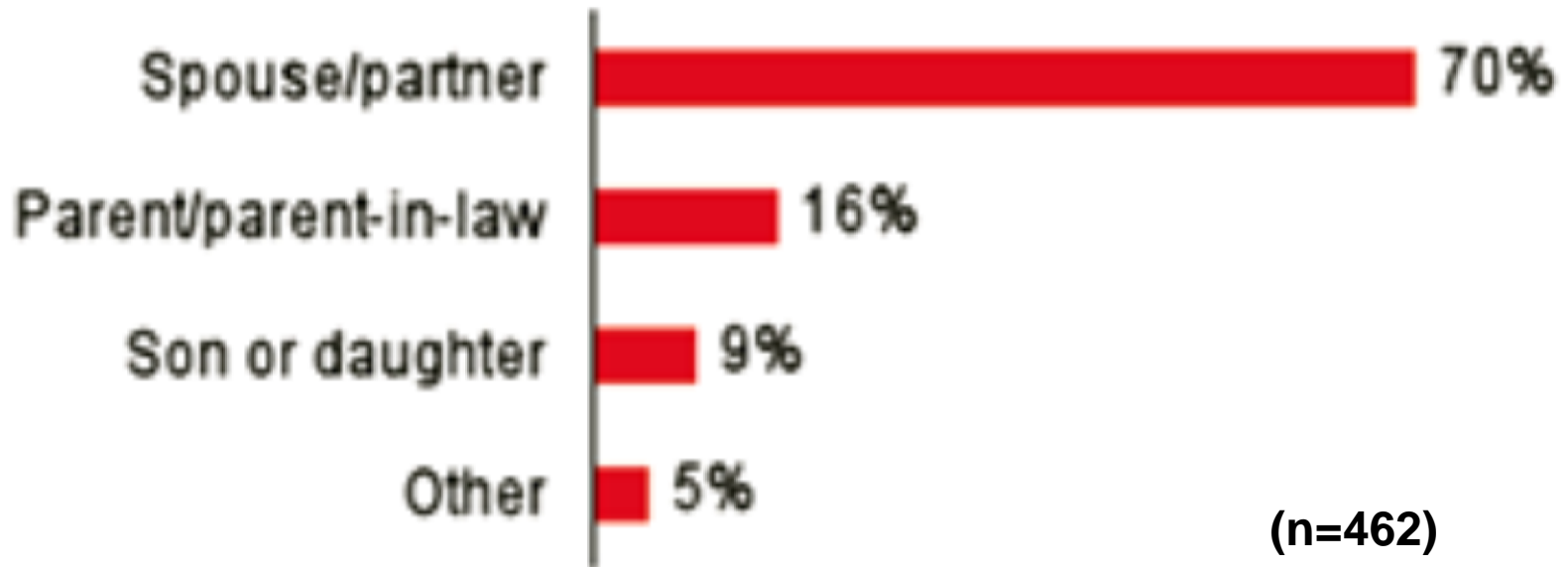
(Caregivers of Veterans – Serving the Homefront Study, 2010)

Caregiving - Did We Have a Choice?



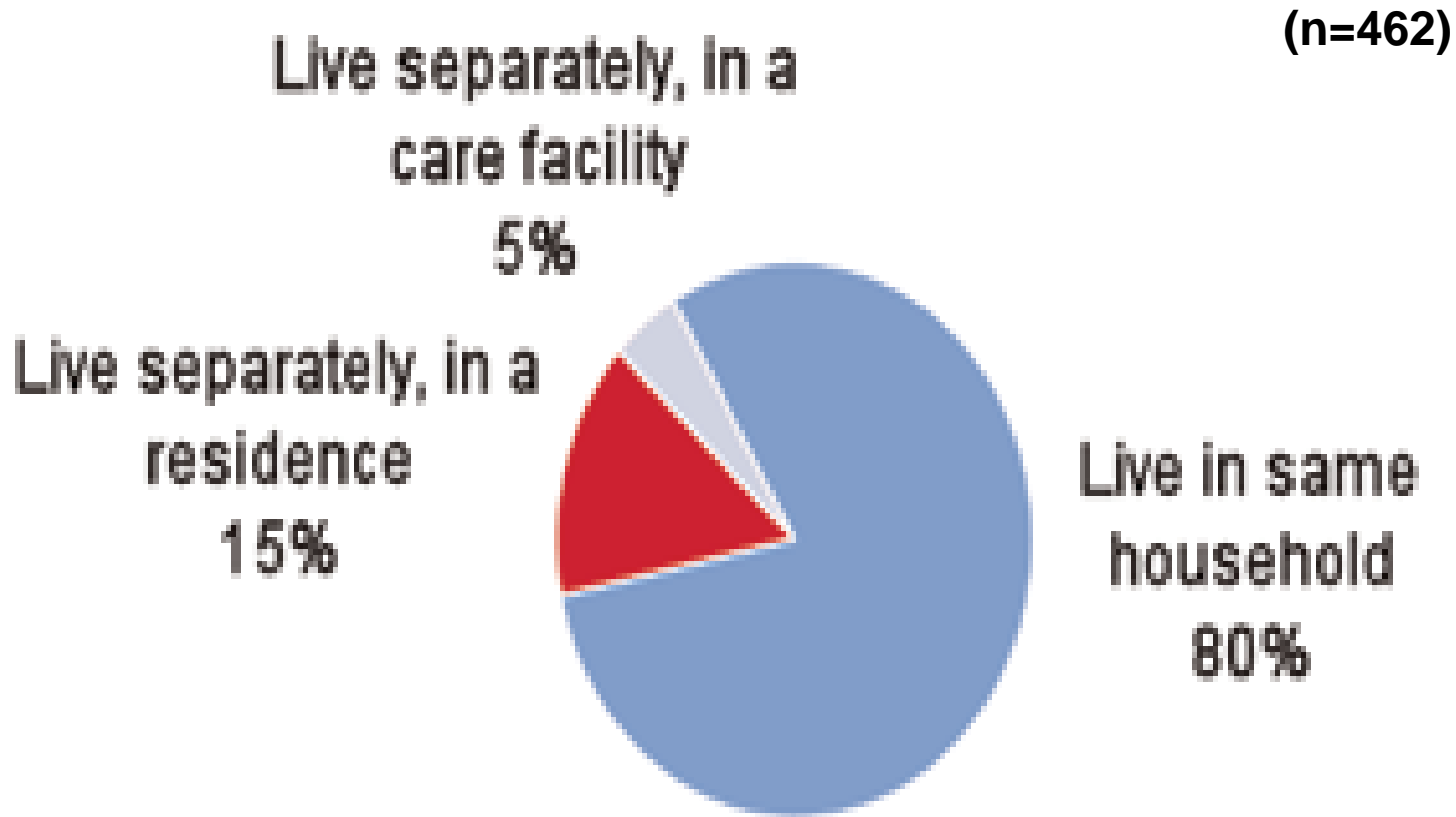
(Caregivers of Veterans – Serving the Homefront Study, 2010)

Who are the Caregivers?



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Who are the Caregivers?



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Caregiver Demographics

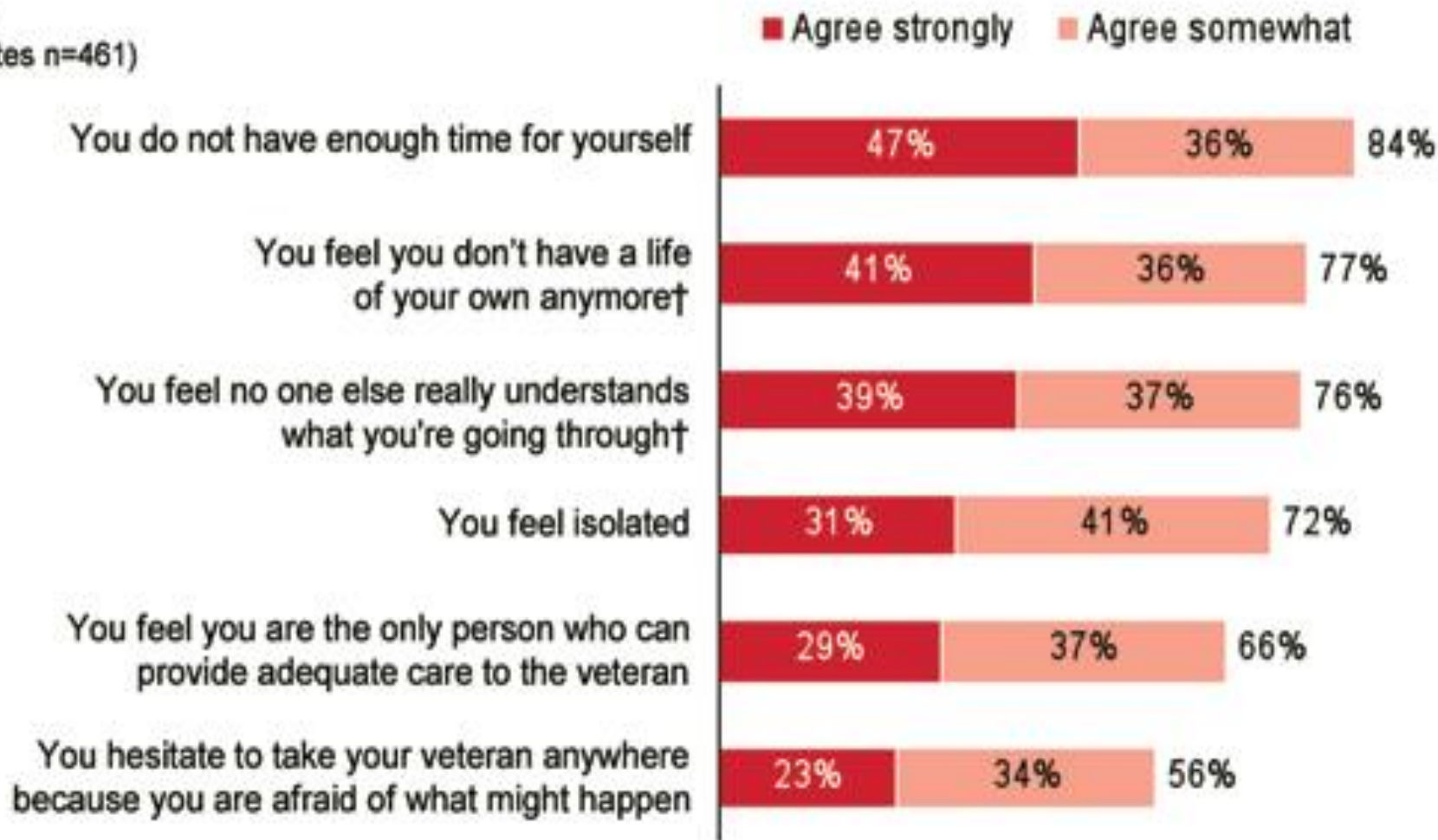
Veteran vs. National Statistics

	Caregivers of Veterans (n = 462)	Caregivers of Adults Nationally (n = 1,307)
Female caregiver	96%	65%
Spousal caregiver	70%	6%
Caregiver lives with care recipient	80%	23%
Primary caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

(Caregivers of Veterans – Serving the Homefront Study, 2010)

Emotional Impact of Caregiving

All
(n=462)
(† indicates n=461)



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Top Challenges Faced by Caregivers of Veterans



Bing Images

Each experienced by at least 2/3 Caregivers:

1. Not knowing what to expect medically with Veteran's condition
2. Not being aware of Veterans Affairs (VA) services that could help
3. Not knowing how to address PTSD or mental illness
4. Difficulty getting through bureaucracies in order to obtain services
5. Not knowing where to obtain financial assistance
6. Not knowing where to turn to arrange a break from caregiving
7. Not knowing where to obtain specialized care

(Caregivers of Veterans – Serving the Homefront Study, 2010)

MSCoE Caregiver Research



Centers of
Excellence
www.va.gov/ms

Veterans with MS Perception of Caregiving:

- Male Veterans w/MS who are married/living with someone, and/or RRMS reported high level of support from their Caregiver. Higher than married women Veterans w/MS.
(Williams, Turner, Haselkorn, et al., 2004)
- Greater global perceived social support from Veteran & greater affectionate support from Caregiver, less depression in Veteran.
- Men with MS reporting greater overall perceived social support and greater perceived emotional/information and tangible support compared with women with MS.

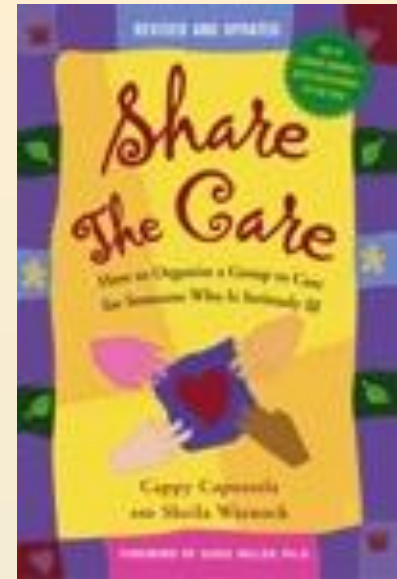
(Bambara, Turner, Williams & Haselkorn, 2010)

Caregivers of Veterans w/MS

- “Supportive qualities” of Caregiver significant for better DMT adherence.
(Siegel, Turner & Haselkorn, 2008)

“Share the Care” Model

- MS experts like it! (Holland, Schneider, Rapp, Kalb, 2011)
- Developed by “caregiver friends” of a friend with cancer.
- Family, neighbors, business associates and acquaintances - turns them into a powerful caregiver "family".
- Uses volunteer care coordinators to bring in family, friends, church groups, and others who can help with care needs and provide respite for caregivers.
- www.sharethecare.org



Other Person-Centered Tools

- Online calendars for caregiver “sharing”:

www.carecalendar.org

www.caringbridge.org

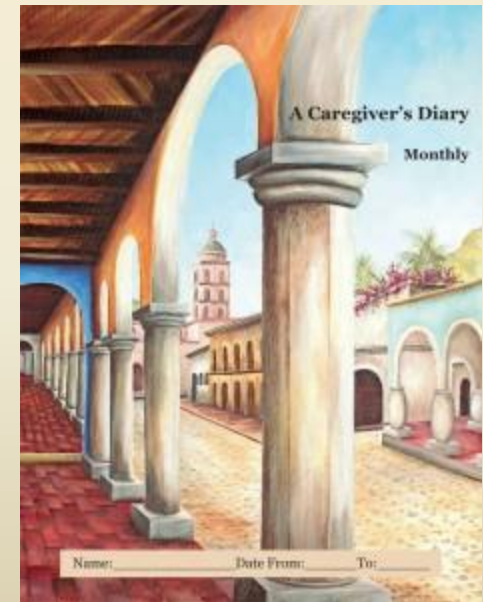
www.takethemameal.com



- Caregiver planning diary:

www.acaregiversdiary.com

- ☒ Daily Documentation
- ☒ Organizing Daily Programs
- ☒ Health and Nutrition Medications/Vitamins
- ☒ Exercise and Hygiene
- ☒ Doctor Appointments and Outings
- ☒ Doctor Contact Information
- ☒ Pharmacy and Prescription Information
- ☒ Documentation transcribed to Doctors



Family Caregiving 101 Website



- National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) collaboration
- Leaders in the movement to better understand and assist family caregivers
- “It’s not all up to you!”
- www.familycaregiving101.org
- Assist a caregiver: www.familycaregiving101.org/assist
- Tips on how to communicate with a Caregiver in order to help: www.familycaregiving101.org/assist/communicating.cfm
- Links to online depression screening (Patient Health Questionnaire "PHQ-9"):
http://www.mentalhealthamerica.net/llw/depression_screen.cfm
- Caregiver Focus Group Study (next slide)

Websites

VA Websites

- VA Caregiver Website Toolbox: www.caregiver.va.gov/toolbox_landing.asp
- VA MSCOE website: www.va.gov/ms/
- VA Spinal Cord Injury/Disorders website: www.sci.va.gov

Other Websites for Caregivers

- American Academy of Family Physicians - A Practical Guide to Caring for Caregivers (with Zarit Burden Scale): www.aafp.org/afp/2000/1215/p2613.html?printable=afp
- University of Alabama at Birmingham - Caring for Caregivers - SCI InfoSheet #17: www.spinalcord.uab.edu/show.asp?durki=22479
- Christopher and Dana Reeve Foundation: www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453201/k.1B08/Caregivers.htm
- Communication Tips & Assisting a Caregiver: www.familycaregiving101.org/assist
www.familycaregiving101.org/assist/communicating.cfm
- Consortium of MS Centers (CMSC): www.mscares.org/cmcs/News/Web-Sights-MS-Caregivers-2.html
- National MS Society: www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/index.aspx
- Paralyzed Veterans of America: www.pva.org/site/c.ajlRK9NJLcJ2E/b.6306123/k.B389/Caregivers_Support.htm
- Rosalynn Carter Institute for Caregiving: www.rosalynncarter.org
- Spinal Cord Injury Information Network: www.spinalcord.uab.edu/show.asp?durki=21680&site=1021&return=21830
- United Spinal Association: <http://www.unitedspinal.org/2011/11/15/help-support-our-caregivers/>
- Website caregivers to other caregivers, personalized information, and local resources: www.agingcare.com/Caregiver-Support

Websites

- Online calendars for caregiver “sharing”:
www.carecalendar.org
www.caringbridge.org
www.takethemameal.com
- Caregiver planning diary: www.acaregiversdiary.com
- Caregiver book: www.sharethecare.org
- Caregiver support and sharing:
www.familycaregiving101.org

Caregiving Research Resources

Note: To connect directly to websites listed, make sure you are in “Slide Show” view and hover mouse over hyperlink and click.

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Caregiving Research Resources

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Caregiving Research Resources

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